



# **The Pernicious Anaemia Society's Data Protection Policy.**

**Updated February, 2026**  
**Next review: February 2027**

## Data Protection Policy

1. The Pernicious Anaemia Society holds three types of information which are covered by this policy.
  - a. **Organisational Information** – this is mostly information which is publicly available but can also contain some personal information.
  - b. **Personal Information** – including the names, addresses and date of birth of members of the society and perhaps their families and friends.
  - c. **Sensitive Personal Information** – this will usually be information about any employees or volunteers. However, the society acknowledges and recognises that it can hold sensitive information about other people, including Trustees, Members and Visitors to any meetings or seminars or to any offices occupied by the society. An example of this would be that the dietary requirements at the Annual General Meeting might allow a person's religion to be deduced, or the sexual orientation of a person might be disclosed by the person on the society's online forum.

Whilst information about organisations is not covered by the Data Protection Act there is some ambiguity about whether certain information is personal or organisational. For example, the contact details for a medical professional might be his or her home address. Because the Pernicious Anaemia Society seeks to comply fully with all relevant legislation organisational information is covered by this policy.

2. The organisations and people about which The Pernicious Anaemia Society holds information are referred to in this policy document as Data Subjects.
3. The Pernicious Anaemia Society will hold information about individuals only with their consent.
4. The Pernicious Anaemia Society will hold information only for specific purposes. It will inform data subjects that their personal information is held in order to:
  - a. Communicate with the data subject any information relating to the society, developments in the diagnosis and treatment of Pernicious Anaemia or any other relevant information that would be of interest to the data subject.

- b.** Analyse the demographic and geodemographic incidence of Pernicious Anaemia.
- c.** Know the number of members of the society.

**5.** The Pernicious Anaemia Society will inform all data subjects if the purposes in 4 change. The only exception to this is that the Pernicious Anaemia Society will make it clear to members that it is a condition of their membership that the society will decide what should happen to information supplied about any organisation that is a member. This will not apply to individuals within the organisation other than the names of post holders.

**6.** No information about members will be kept once it is no longer required for its stated purpose.

**7.** The Pernicious Anaemia Society will strive to ensure that the information that it holds about data subjects is accurate by ensuring that data subjects can update the information held about them.

**8.** Data subjects will not receive marketing mailings from the Pernicious Anaemia Society or any other organisation other than in relation to 4a above.

**9.** Data Subjects will be entitled to access information held about them by the Pernicious Anaemia Society.

**10.** Information about data subjects will limited to members of the Pernicious Anaemia Society's staff (including volunteer staff) and the Trustees of the Society. Other organisations or individuals will only be allowed access to information about data subjects:

- a.** If there is a legal requirement,
- b.** there is explicit or implied consent to disclose the information by the data subject,
- c.** where the information is publicly available elsewhere.

**11.** The Pernicious Anaemia Society has procedures for ensuring the security of all personal data. Paper records containing confidential personal data is disposed of in a secure way using a cross shredder.

**12.** The Pernicious Anaemia Society has a set of procedures (see appendix 1) covering all areas of its work which it follows to ensure that it achieves the aims set out above.

**13.** The Society's Office Manager has been designated as the Data Protection Compliance Officer for the Pernicious Anaemia Society.

**14.** At the beginning of any new project or activity the member of staff, or volunteer member of staff, or Trustee or member of any committee will consult with the Data Protection Officer about any data protection implication relating to the project or activity.

**15.** There may be times where the Pernicious Anaemia Society works in partnership with other organisations on projects which require data sharing. The society will always clarify which organisation is to be the Data Controller and will ensure that the Data Controller deals correctly with any data which the Pernicious Anaemia Society has collected and maybe shared with the other organisation.

**16.** All new staff and volunteers will be given training on the data protection policy and procedures.

**17.** The Pernicious Anaemia Society will carry out an annual review of its data protection policy and procedures.

## Appendix One:

### **The procedures for ensuring compliance with the Pernicious Anaemia Society's Data Protection Policy.**

1. All volunteers and all staff will be made aware of, and given a copy of, this policy document.
2. This policy document will be made available to members of the Pernicious Anaemia Society.
3. All volunteers and staff will be instructed in the correct destruction of any personal data as part of their induction training.
4. This policy will be reviewed annually and the dates for review are as follows:

February 2026 Review Completed Signed by Data Protection Compliance Officer

Signed \_\_\_\_\_ Date \_\_\_\_\_

Name \_\_\_\_\_

ENDS